DOCUMENT RESUME

ED 349 722 EC 301 466

AUTHOR Harris, Yvette; And Others
TITLE A Study of Parent-Child Attachments in HIV+/AIDS Minority Families.
PUB DATE 12 Nov 91
NOTE 10p.; Paper presented at the Council for Exceptional Children's Topical Conference on At-Risk Children and Youth (New Orleans, LA, November 10-12, 1991).
PUB TYPE Speeches/Conference Papers (150) -- Reports - Research/Technical (143)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Acquired Immune Deficiency Syndrome; Extended Family; Family Caregivers; Family Involvement; Family Relationship; Family Role; Interviews; *Medical Services; *Minority Groups; *Social Support Groups; *Symptoms (Individual Disorders)

ABSTRACT

This study examined medical services and support services available to and utilized by minority families where a child and/or parent was identified as having Human Immunodeficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS). Sixteen caregivers of children (ages 2-4) diagnosed as HIV positive or children who had been exposed to the HIV/AIDS virus participated in the study. Caregivers were administered the Pediatric AIDS Interview which covered demographic information, child's medical history, medical services, medical management, family and friend support, use of external support services, and coping strategies. Among the results were the following: (1) over 80% of respondents indicated that they were pleased with the quality of their child's medical care; (2) 62% of the participants had informed their immediate family; (3) 70% reported that there were no support groups in the area for families of HIV positive children; (4) coping strategies included praying, going to support meetings, learning about the new developments in AIDS research, focusing on positives, and not thinking about the child's illness; and (5) extended families were called upon to demonstrate an array of caregiving roles. (Contains 11 references.) (JDD)

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A STUDY OF PARENT - CHILD ATTACHMENTS IN HIV+/AIDS MINORITY FAMILIES

ED349722

Dr. Yvette Harris, Ph.D.
Department of Developmental Psychology
Miami University
Oxford, Ohio

Dr. Martha L. Bell Ph.D.
Department of Exceptional Education
University of Central Florida
Orlando, Florida

Dr. Linda Crites, Ph.D.
Social Research Consultant
University of Maryland - Baltimore
Baltimore, Maryland

Presented at CEC Topical Conference on At-Risk Children and Youth.
New Orleans, Louisiana, November 12, 1991

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The relationship between mother and child is one that begins in utero and remains a special bond throughout the child's formative years. The quality of that bond, however, is affected when unusual stresses interfere with or impede the natural bonding process. Peterson (1987) reports that during the early months of life, as the infant engages in reciprocal interactions with the caregiver, a primary attachment or emotional bond is formed with the mother.

The maternal-child attachment cannot be overemphasized, for it is from this and subsequent attachments that the child begins to build a sense of self. Sroufe and Waters (1977) observed that the quality of attachment may be related to a child's exploratory behavior in unfamiliar situations, mastery of the object world, and willingness to engage in interactions with strangers. Blacher and Myers (1983) add that because both parent and child play a part in shaping their interactions, both are capable of jeopardizing the development to normal attachments. Other researchers concur that disturbances in parents' early attitudes toward their newborns can lead to chronic disturbance in their attachment.

For the child and/or parent identified as HIV+/AIDS, several stressers immediately become apparent (Lewert, 1988):

* the disease causes great pain and suffering, and for the most part, is terminal;

* parents of AIDS youngsters suffer tremendous anger and guilt about having transmitted the disease to their loved one; and

* the stigma attached to AIDS; moreover, the stigma is passed on to the family of the AIDS victim.

Scope of Problem

According to the Centers for Disease Control, 80% of pediatric AIDS patients in this country are African-American or Hispanic. Most are indigent (Osterholm, 1987); 80% were born to infected mothers; and many have infected fathers and siblings as well. Figures released by the Association for the Care of Children's Health indicated that while African-American children constitute 15% of the nation's children, they constitute 60% of all childhood AIDS cases. Further, Honey (1988) and Lewert (1988) observed that 80% of the reported pediatric AIDS cases are African-American children under the age of 13. Moreover, while Hispanic youngsters represent 10% of the children in the United States, Hispanic youngsters account for 22% of all childhood AIDS cases. Pediatric HIV disease especially afflicts poor inner city children whose lives are further complicated by social disorganization, and often by parental drug use.

One of the concerns facing parents of HIV positive youngsters has been that of mother-child attachment. Research suggests that individuals with extended support systems generally cope better than those individuals without such identifiable support systems. Thus the concern

becomes that those without support systems, both mothers and children, are "at risk" for additional problems.

Medical health care costs are of vital concern to parents of HIV+/AIDS youngsters. Hegarty (1988) observes that medical health care costs of HIV+ infected children in Harlem amounted to an average. lifetime cost of $90,347 per child. Per diem costs were highest for children with opportunistic infections ($705) and lowest for homeless "boarder babies."

Scope of Study

This study examined effects on the parent-child relationship in minority families where a child and/or parent was identified as HIV+/AIDS.

Through this study, parent-child dynamics were addressed. Ultimately, information, referrals, and relevant suggestions will be offered to the families, caregivers, and policy makers.

This research was guided by four questions:

1. What changes in the family structures have resulted be cause of the illness?
2. What are the families support systems?
3. What is the family's knowledge of available medical and social support services.
4. What is the frequency of use of the available support services?

Method

Participants

The participants were 16 caregivers of two to four year old children diagnosed as HIV positive or children who had been exposed to the HIV/AIDS virus. The participants were recruited from a special head start program for HIV+ families in a major metropolitan urban city. Participants were informed that their willingness to participate or not to participate in the research was voluntary and would not affect the services they were receiving at the head start support center. Of the 16 participants, 15 were female; one was male.

Materials

Pediatric Aids Interview. A 31 item open ended questionnaire was administered to the primary caretaker to obtain information about the following: Demographic Information (age, marital status, highest level of education, occupation; target child's age, target child's sex, target child's birth order; and number of children in the family); Child's Medical History (age of

diagnosis, how the child contracted the virus, frequency of illness, symptoms); Medical Services (doctor's explanation about the child's illness; referral to a social worker and overall satisfaction with child's health care); Medical Management (medication, frequency of medication, who administers the medication, transportation, cost of child's treatment); Family and Friend Support (disclosure, reactions, quality of support); Use of External Support Services (knowledge of support groups, attendance, transportation, satisfaction with support groups); and coping strategies (changes in life, precautions).

Procedures

Primary caregivers were individually administered the Pediatric Aids Interview, by one of the principal investigators in a room located in the Head Start Center or in the participant's home. The interviews took approximately one hour to complete. The caregivers were informed about the confidentiality of their responses and told that their individual responses would be available only to the principal investigators of the research project.

Results

Demographic Information

Participants

Ages of participants ranged from 21 years to 61 years. 10 were single, 2 were married, 3 were divorced and one participant did not indicate marital status.

Educational levels ranged from 7th grade to a college degree.

Child Information

Gender: 68% of the children were female and 32% were males. Birth Order: 31% were first born, 25% were second born, 25% were third born, 12% were fourth born and 7% were born last.

Number of Children in Family

31% of the children were only children and the remaining 69% of the children had two or more siblings.

Child's Medical History

Age of diagnosis: 30% of the children were diagnosed at birth, 6% at 4 months, 12 % at 9 months, 6% at 10 months, 6% at 3 years and 40% are presently HIV negative.

Symptoms Prior to the Diagnosis

The symptoms ranged from thrush, pneumonia, rashes, nose bleeds, fevers, ear infections, to delay in development.

Numbers of children diagnosed as HIV+

Of the families interviewed, 60% reported that one child in the family had tested HIV+; 40% indicated that no children in the unit, as yet, had tested positive.

How Was the Illness Discovered

Of the children testing positive for the virus, 50% were diagnosed at birth; 30% were diagnosed through a continuing medical complaint; 20% of the children were diagnosed through a routine physical.

How Did the Child Contract the Virus

74% of the children contracted the virus through the mother, 12% through the dad, and 14% of the respondents were unsure.

How Often Is Your Child Ill

The responses ranged from frequently (every two weeks, monthly) to rarely (admitted twice for blood infection).

What Are the Symptoms

The symptoms ranged from colds, ear infections, fever, rash, thrush, and nose bleeds.

Medical Services

Quality of Child's Health Care?

Over 80% of the respondents indicated that they were pleased with the quality of their child's care; 20% indicated that improvement was needed in doctors communicating with parents.

Doctor's Explanation of Child's Illness?

Of those families responding to this question, slightly more than 80% indicated that the doctor was direct and frank, while 10% were referred to a Specialty Clinic. Still in another 10% of the cases, doctors told another member of the family.

Did the Doctor Refer You to a Social Worker?

40% of the families were referred to a social worker; 40% of the families already were working with a social worker; 20% of the families were not referred to a social worker.

Medical Management

Is the child presently being treated for the virus? 60% are presently being treated with AZT and or some other drugs such as catheprel, IVIG, aeresol, pentamidine, nystatin, immunoglobulin. 40% of the children are not being treated and the following reasons were offered: the child tested negative, the child is not showing symptoms, or not displaying the symptoms consistently.

Who administers the medication?

Of the children that receive medication, the medication is administered by family members 60% of the time; or by a hospital, clinic, or home health agency 40% of the time.

Cost and Payment of Treatments. Of those families in need of medical treatment, 100% of them qualified for medical assistance.

Transportation

40% indicated that a cab was provided by the clinic or hospital where the family was being served; 20% used personal transportation; 20% used public transportation; and 20% used both public and personal transportation.

Informing Family Members and Friends

62% of the participants have informed their immediate family, 12% have told no one, and 26% have informed some, but not all family members.

Disclosure to Family Members

In 10% of the cases, an infected parent had told a family member about her illness, but not about the illness of her sick child; 10% of the participants had told no one. In 10% of the cases, the primary caregiver shared the information; in 10% of the cases, another member of the family did so.

Reactions of Family Members

Reactions ranged from confused, worried, disbelief, shocked, sad, understanding to supportive.

Did the family relationships change?

The responses to this answer ranged from no changes, feelings of isolation, support, not wanting the child around, to family is closer, communication is better.

Who outside the family knows?

Responses ranged from close friends (friends, godparents, roommate, family network) to school and medical staff.

Disclosure to Other Persons

60% reported that they informed the other people, 10% reported that friends or family members disclosed a confidence, 10% indicated that the disclosure was through voluntary disclosure and through others; 20% reported that no one outside of the family knew.

Use of External Support Services

Knowledge of support groups.

30% reported that there are support groups in the area for families of HIV positive children, 70% reported that there were no services available in the area, or no services that they were aware of.

Attendance at support groups - 70% of those responding reported that they did not attend the support groups, 20% stated that they stopped attending, 10% reported that they are presently attending.

DISCUSSION

Caring for a special needs child is a monumental task in itself. Researchers note that parents of special needs children deal with feelings of guilt, failure, self doubt, resentment and anger, while at the same time dealing with the excessiv demands imposed upon them by their special needs children (Paul, 1981).

The situation becomes more complex, however, when the special needs child is ill and in most instances, the mother or primary caregiver is ill as well. In some cases, the home situation is tenuous, and family units are often divided.

Such is the case of families with pediatric HIV positive children. Hutchings (1988) notes the Public Health Service predicts an increase of nearly 350% in Pediatric AIDS cases by 1991. Moreover, the Citizens' Committee for Children, an advocacy group in New York City, adds that for every officially reported case of pediatric AIDS in New York City, there are five symptomatic HIV infected children not reported.

In this study, primary caregivers ranged from grandmother to aunt to foster mother. At least two of the natural mothers were incarcerated. In another instance, a great aunt, had legal custody. In over 3/4ths of the cases cited, primary caregivers indicated spending a larger amount of time with the child who had been diagnosed as HIV+/AIDS.

Further, informal rather than former support groups, were used by most of the participants. This represents an integral part of African-American family strengths, wherein family members turn to other family members for strength and comfort during a crisis.

It is also important to note that infected parents were very careful to take their children for clinic appointments, even when the infected parents would not keep their personal appointments. Still, in another instance, the infected parent assumed no responsibility for her child, and both the parent and mother were being cared for by the grandmother.

A variety of coping strategies emerged. Strategies ranged from praying, talking to others, going to support meetings, spending time alone, learning about the new developments in AIDS research, to focusing on the positives and not thinking about the child's illness.

At least two limitations were apparent in this study. First, the sample size was very small and dealt with a specific group of participants at a model support program for HIV+/AIDS families. Additionally, some respondents did not respond to all of the questions, and some responses were deemed "unscorable". Further, the term "parent" was often used generically to include any of the primary caregivers. When a natural parent was not available, the primary caregiver provided the necessary information.

A writer in a local urban newspaper, in discussing research dealing with African-Americans, reasoned that "offering research that confirms and offers the language and logic of the pathology does no good." Such is the case of the issue of AIDS and the African-American families. To identify the issues and offer no plausible solutions is ineffectual and offers minimal "credence" to an already devastating issue.

Although this study involved a small sample in a very specific setting, it is very clear that the extended family is called up to demonstrate an array of roles -- often overtaxing the family unit. For example, in some families, where the primary caregiver was incarcerated, a relative not only cared for the HIV+ child, but also additional siblings as well; in many cases, the guardian had children of her own that needed to be cared for. In this study, follow-up on these families will occur, especially as the disease progresses, to further document if any changes occur in the parent-child relationship.

As noted by The Task Force on Pediatric AIDS (1989), AIDS is more than a medical problem. Therefore, treatment and intervention requires assistance of numerous professionals and family members - all commited to combatting the problems that the disease poses to children, families, and society.

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